

RESEARCH DESIGNS & APPROACHES FOR STUDYING STIGMA

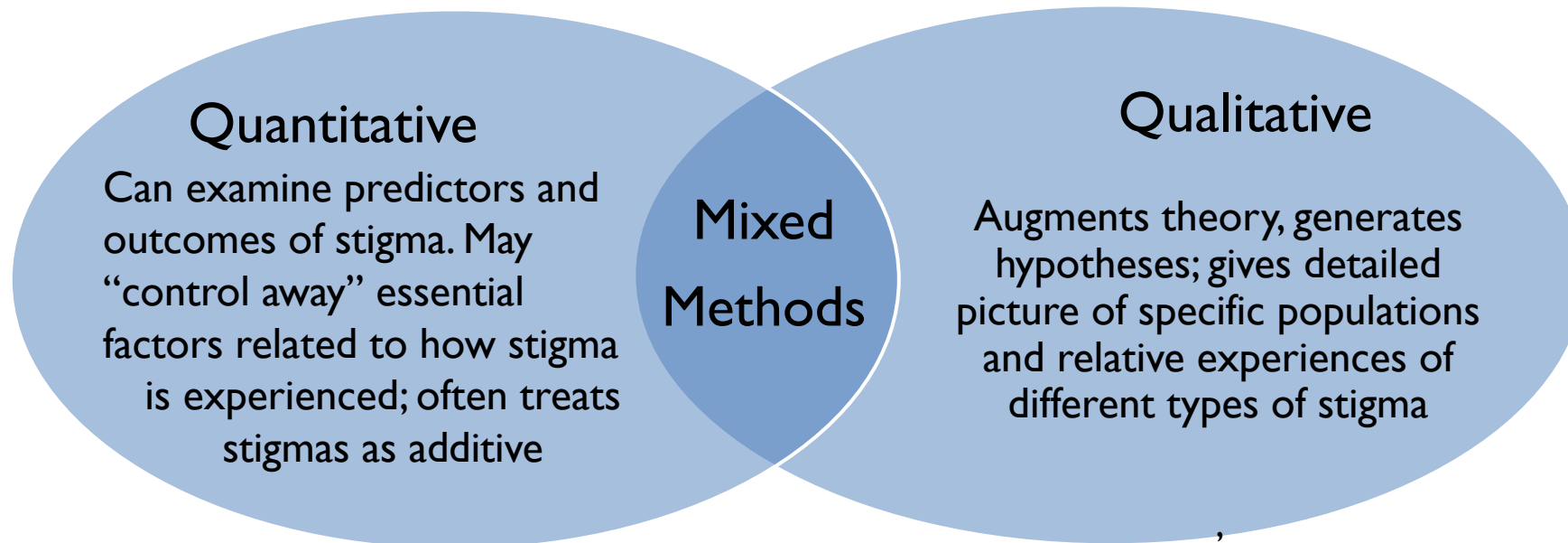
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Approaches for Studying Stigma



**Slide adapted from Sara Murray, Society of Behavioral Medicine, 2019*

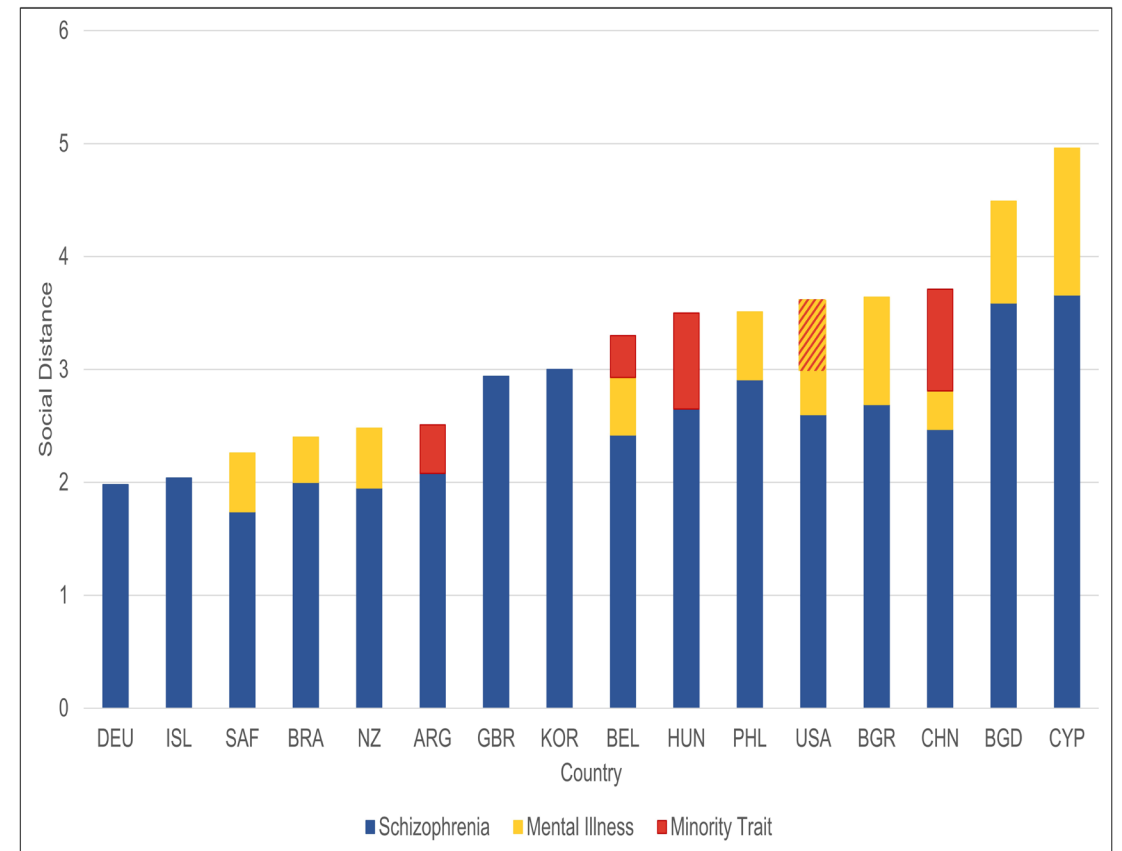
Quantitative approaches (observational)

Assessing stigma in the general public and/or specific populations that may perpetuate stigma (e.g., health workers):

- Surveys of the general public
 - ▣ Multi-item scales
 - ▣ Vignettes
 - ▣ Implicit bias assessments
- Experimental psychology laboratory studies
- Geospatial analysis
- Law and policy studies
- Prototype studies

Example: The Stigma in Global Content-Mental Health Study (SGC-MHS)*

- Conducted face-to-face interviews with nationally representative samples of adults on every continent (17 countries).
- Participants were provided a vignette describing an individual with schizophrenia and asked about willingness to interact with that person across six social settings, including work, neighborhood, and marriage into the family.
- Vignettes randomly varied characteristics including a second stigmatized condition that constituted an "outgroup" (e.g. race/ethnicity/region) in that society.



Quantitative approaches (observational)

Assessing stigma in those with stigmatized identities:

- Multi-item questionnaires
 - ▣ Cross-sectional
 - ▣ Longitudinal
- Experience sampling method (ESM) aka Ecological Momentary Assessment (EMA)


Outcomes often examined in stigma research

- Health Behaviors
 - ▣ Prevention
 - ▣ Treatment
 - ▣ Adherence
- Mental Health
 - ▣ Depression
 - ▣ Anxiety
 - ▣ Stress
 - ▣ Substance Use
- Biomarkers
 - ▣ Cortisol
 - ▣ Viral load
 - ▣ Immune and inflammatory markers



Example: Using ESM to study stigma in Birmingham Alabama*

- N = 109 men living with HIV
- Gave participants smart phones
- Texted / emailed them at random times during the day and asked them to answer questions using smart phones
- 3 times a day, for 7 days; example questions:
 - **Right now**, how ashamed do you feel because of your HIV status?
 - **Right now**, how confident do you feel that you can stick to your treatment plan for your HIV status?
 - Since your last report, did somebody treat you negatively because of your race (sexual orientation, HIV status)
 - Since your last report, how much did someone give you support related to your HIV status? ...



Discussion: Other observational quantitative study designs for the study of stigma that you have used or are aware of?

Qualitative Approach and Methodological options

- Approaches:
 - ▣ Grounded theory
 - ▣ Phenomenology
 - ▣ Narratives
 - ▣ Case Studies
 - ▣ Ethnography
 - ▣ Etc.
- Classic qualitative data collection methods
 - ▣ In-depth interviews
 - ▣ Cognitive interviews
 - ▣ Focus groups
 - ▣ Observation (part or non-part)
 - ▣ Content analysis of documents, websites, video, art, etc.
 - ▣ Etc.

* See upcoming session on qualitative methods to study stigma

Example: Focus groups and cognitive interviews

Social Norms and Stigma Regarding Unintended Pregnancy and Pregnancy Decisions: A Qualitative Study of Young Women in Alabama

CONTEXT: *Social norms and stigma may play important roles in reproductive health behavior and decision making among young women in the U.S. South, who disproportionately experience unintended pregnancies. No research has described the presence and manifestations of social norms and stigmas associated with unintended pregnancy and related decision making from the perspective of this population.*

METHODS: *Six focus groups and 12 cognitive interviews were conducted between December 2013 and July 2014 with 46 low-income women aged 19–24 living in Birmingham, Alabama; respondents were recruited from two public health department centers and a community college. Semistructured interview guides were used to facilitate discussion about social perceptions of unintended pregnancy and related pregnancy decisions. Sessions were audio-recorded, and transcripts were analyzed using a theme-based approach.*

RESULTS: *Participants described community expectations that pregnancy occur in the context of monogamous relationships, in which both partners are mature, educated and financially stable. However, respondents reported*

By Whitney Smith, Janet M. Turan, Kari White, Kristi L. Stringer, Anna Helova, Tina Simpson and Kate Cockrill

Whitney Smith and Anna Helova are doctoral candidates, Janet M. Turan is professor and Kari White is

Less-Used, Innovative Qualitative Methods

- Photo-Voice
- Mystery Shopper approaches
- Longitudinal (repeated) qualitative interviews
- Dyadic qualitative studies
- Analyses of social media posts
- Virtual focus group methods
 - ▣ e.g., asynchronous online focus groups with female-to-male trans masculine (TM) transgender individuals (Reisner et al., *Qual Health Research*, 2018)

Example: Mystery Shoppers

Testing the Testers: Are Young Men Who Have Sex With Men Receiving Adequate HIV Testing and Counseling Services?

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Background: The United States Centers for Disease Control and Prevention promote HIV testing every 6 months among young men who have sex with men (YMSM) to facilitate entry into the HIV prevention and care continuum. Willingness to be tested may be influenced by testing services' quality. Using a novel mystery shopper methodology, we assessed YMSM's testing experiences in 3 cities and recommend service delivery improvements.

Methods: We assessed YMSM's experiences at HIV testing sites in Philadelphia (n = 30), Atlanta (n = 17), and Houston (n = 19). YMSM (18–24) were trained as mystery shoppers and each site was

visited twice. After each visit, shoppers completed a quality assurance survey to evaluate their experience. Data were pooled across sites, normed as percentages, and compared across cities.


Results: Across cities, visits averaged 30 minutes (SD = 25.5) and were perceived as welcoming and friendly (70.9%). YMSM perceived most sites respected their privacy and confidentiality (84.3%). YMSM noted deficiencies in providers' competencies with sexual minorities (63.4%) and comfort during the visit (65.7%). Sites underperformed on Lesbian, Gay, Bisexual, Transgender visibility (49.6%) and medical forms inclusivity (57.95%). Sites on average did not discuss YMSM's relationship context (49.8%) nor provide risk reduction counseling (56.8%) or safer sex education (24.3%). Sites delivered pre-exposure prophylaxis information and counseling inconsistently (58.8%).

Received for publication August 9, 2019; accepted August 14, 2019.

Example: Longitudinal Qualitative Interviews*

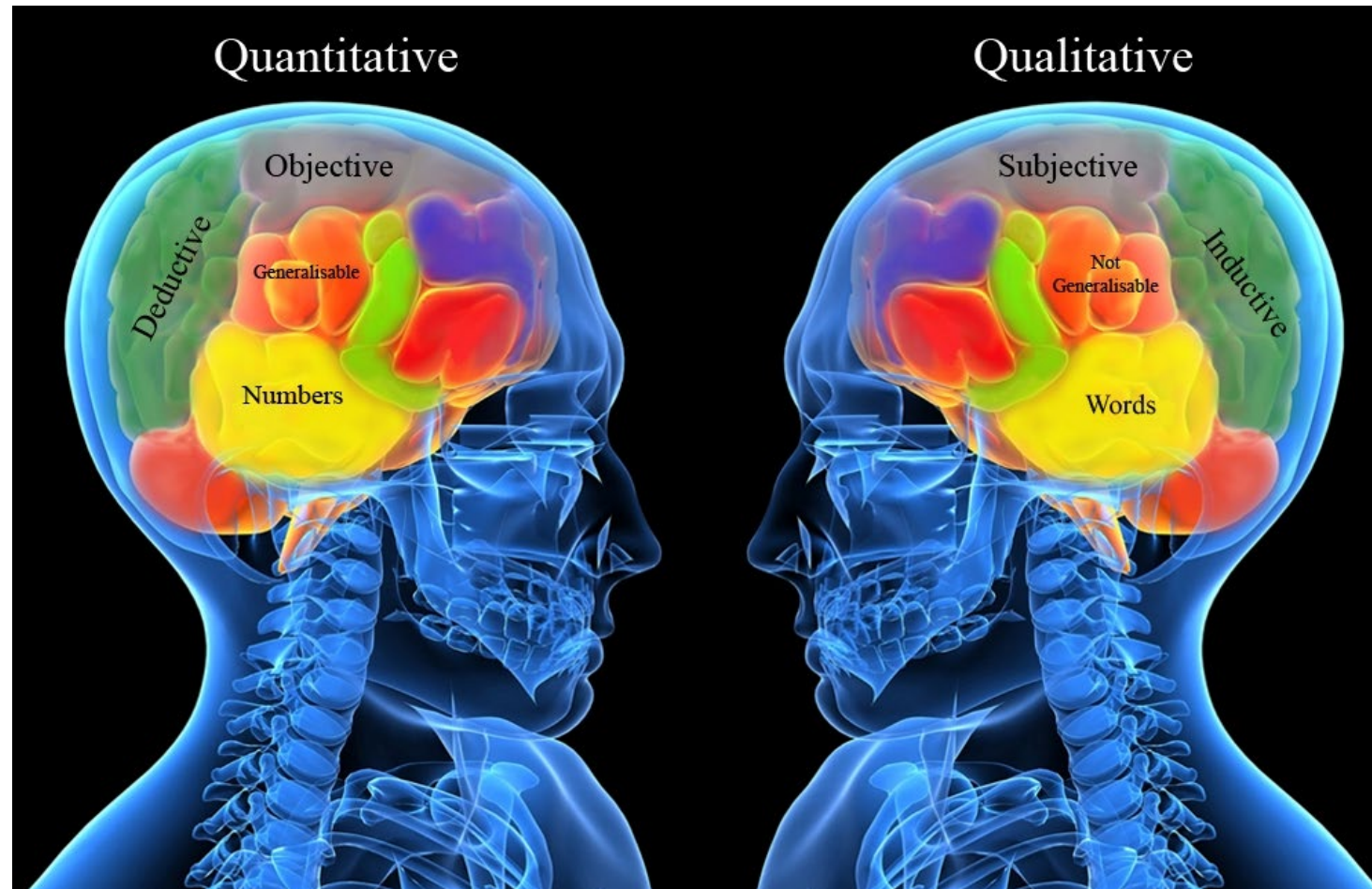
- Longitudinal, qualitative research integrated into a randomized trial of a livelihood intervention to understand processes and mechanisms for how the intervention may affect stigma and mental health among HIV-infected Kenyan adults
- In-depth interviews were conducted with intervention participants and control participants at two timepoints (after intervention start and upon intervention end)
- Interviews were translated, double-coded, and analyzed thematically using an inductive-deductive team approach.





□ Discussion: What other examples of innovative qualitative research designs to study stigma are you aware of?

Mixed Methods Approaches



Core Characteristics of Mixed Methods Research

In mixed methods, the researcher:

- 🔗🕒 collects and analyzes persuasively and rigorously both qualitative and quantitative data
- 🔗🕒 mixes the two forms of data concurrently, sequentially, or embedding one within the other
- 🔗🕒 gives priority to one or to both forms of data

Six Popular Mixed Methods Designs (Creswell & Plano Clark, 2011)

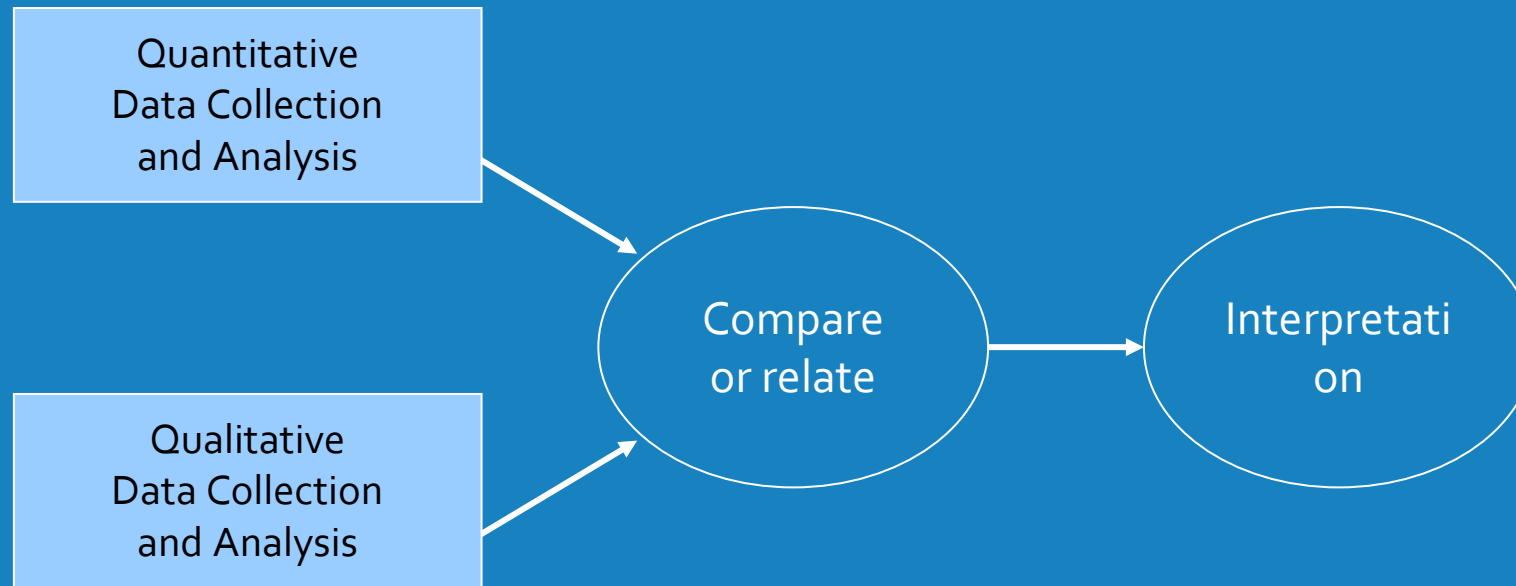
Basic Designs

- Convergent Parallel Design
- Explanatory Sequential Design
- Exploratory Sequential Design

Advanced Designs

- Embedded Design / Intervention Design
- Transformative Design (the Social Justice Design)
- Multiphase Design

THE CONVERGENT PARALLEL DESIGN



CONVERGENT

The MAMAS Study

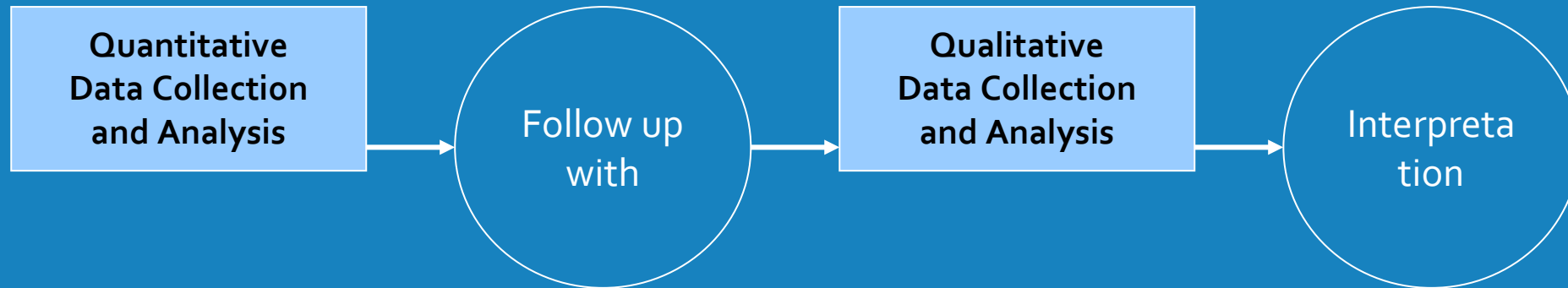
Maternity in Migori and AIDS Stigma Study

Investigating the relationships between women's perceptions and experiences of HIV/AIDS stigma and their use of essential maternity and HIV services*

- 1 777 pregnant women who didn't know their HIV status participated in questionnaires before their first ANC visit and a sub-set were followed-up in late pregnancy and after the birth
- Qualitative in-depth interviews with community health workers, childbearing women, and family members (n = 48)

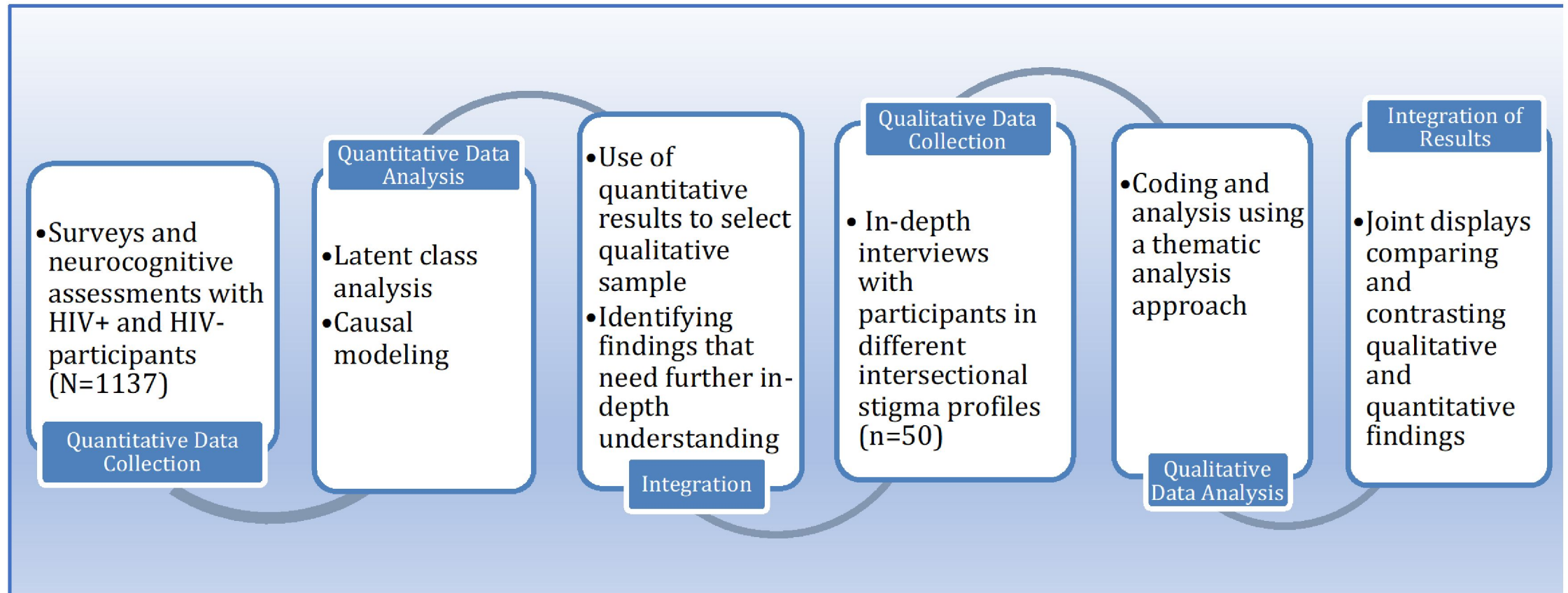


THE EXPLANATORY SEQUENTIAL DESIGN

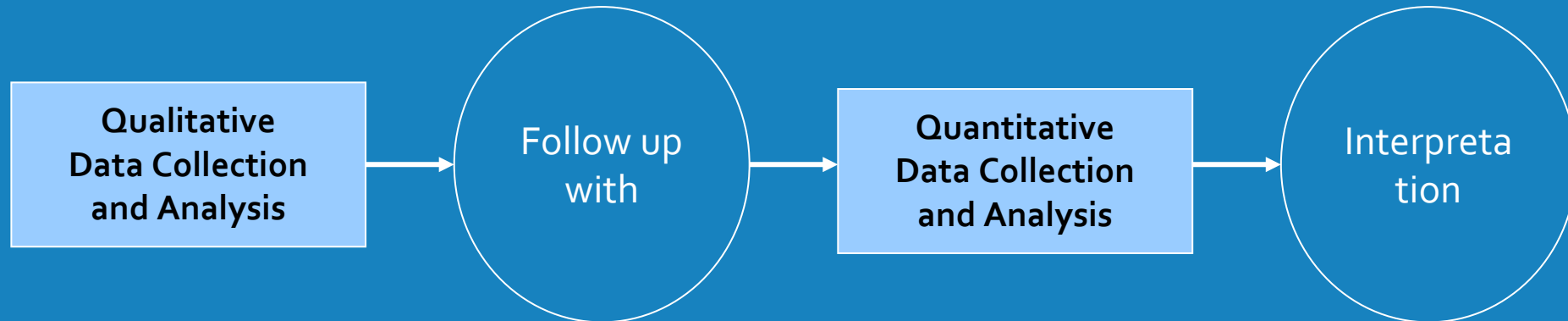


EXPLANATORY

Example: Explanatory Sequential Design

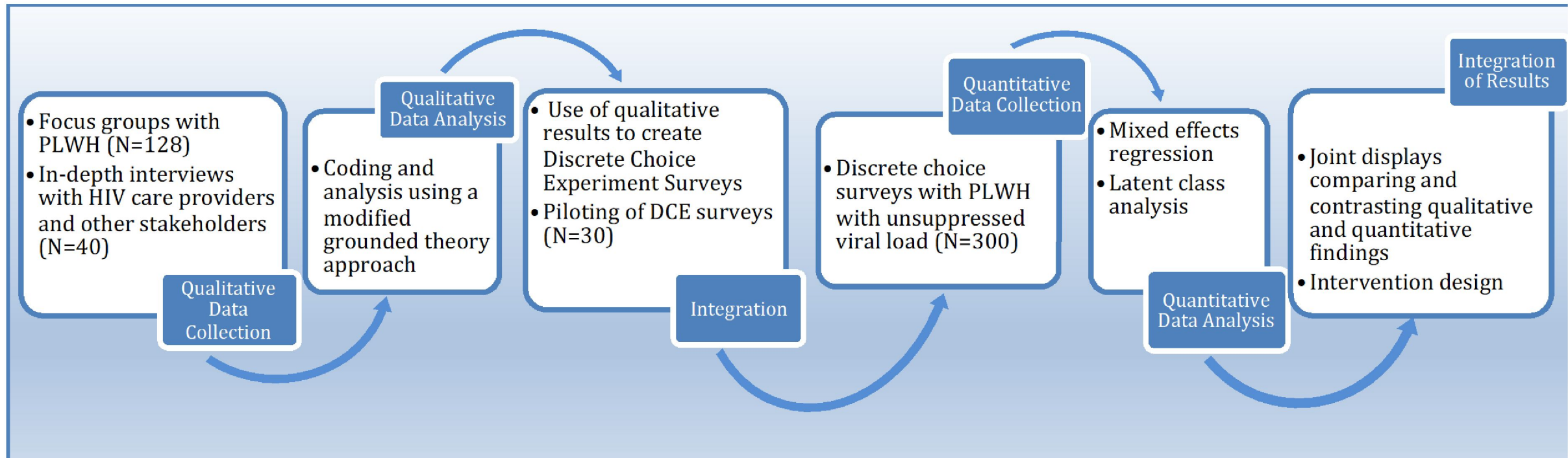


THE EXPLORATORY SEQUENTIAL DESIGN



EXPLORATORY

Example: Exploratory Sequential Design

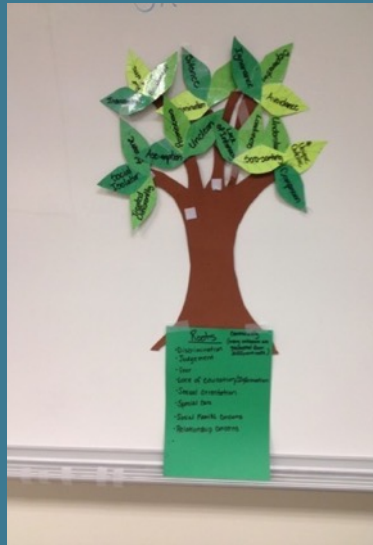


Intervention Studies

- Pre-post designs of stigma-reduction interventions
- Trials of stigma-reduction interventions
 - ▣ Individually randomized
 - ▣ Cluster randomized
 - ▣ Stepped wedge
- Implementation science hybrid designs

The FRESH Intervention (Finding Respect and Ending Stigma around HIV)*

- An intervention to reduce HIV-related stigma and discrimination in healthcare settings*



Pre- and Post-Questionnaires

Health Workers:

- Socio-demographics
- Stigma scales
- Discrimination experiences (race, gender, SES, etc.)
- Risk perception
- HIV knowledge
- Empathy
- Contact
- Workshop experience

Consumers:

- Socio-demographics
- Patient empowerment
- HIV-related self-efficacy
- Stigma scales
- Discrimination experiences (race, gender, SES, etc.)
- Self-esteem
- Coping
- Workshop experience

Example: Individual Randomized Trial

- Still Climbin'* is an intervention for Discrimination-Related Coping Among HIV-Positive Black Sexual Minority Men
- 8 weekly group sessions and a graduation session, based on principles of cognitive behavior therapy.
- Sixty-four HIV-positive Black sexual minority men were recruited from community venues; 38 were randomized to the intervention and 26 to a wait-list control group.
- Participants completed assessments at baseline and 3- and 6-months postbaseline. Intervention participants completed postsession feedback forms.

*Bogart et al., *Cultural Diversity and Ethnic Minority Psychology*, 2018

Example: Cluster randomized Trial

- The DriSti Trial* tested an easily adaptable, mostly tablet administered, interactive stigma-reduction intervention for healthcare providers in India, delivered to ward staff (n = 1,557) and nursing students (n= 1,625) in 62 Indian institutions
- The team randomly assigned 15 nursing colleges and 17 hospitals to the intervention, and 13 nursing colleges and 17 hospitals to the wait-list control
- Follow-up at six months after the intervention

Example: Implementation Science Hybrid Design

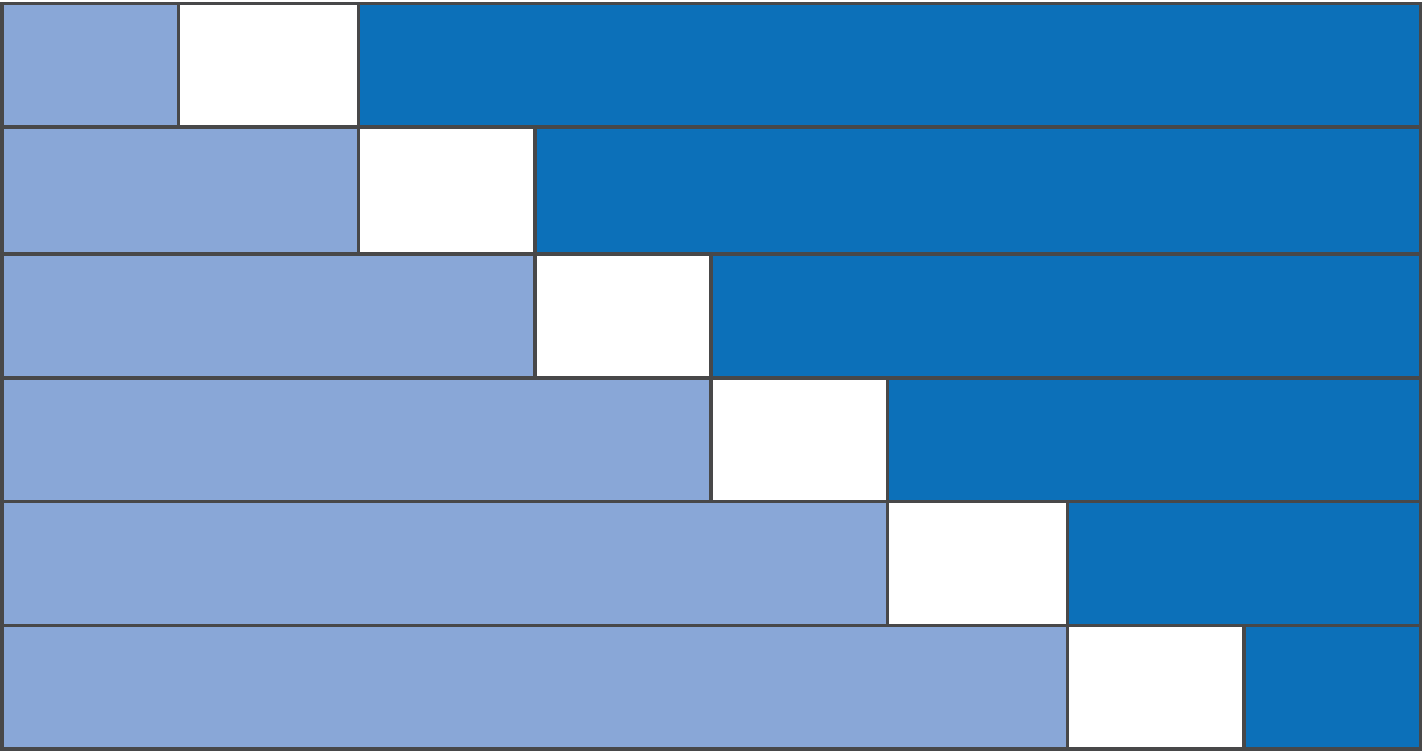
- **Adapting and Pilot-Testing a Behavioral Intervention to Incorporate Advances in HIV Prevention for Black Young MSM in Alabama (PI: H. Budhwani)***

- Aim 3: Conduct a **hybrid type 1 effectiveness-implementation pilot study** of the adapted intervention to a) assess acceptability and feasibility of the adapted intervention; b) preliminarily estimate effects on HIV prevention outcomes; and c) collect data on real-world implementation.

- Approach:
 - ▣ Pilot-test the intervention with African American or Black YMSM in Alabama (half will be randomized to the control condition; half will receive the intervention).
 - ▣ Collect implementation data from staff interviewed in Aim 1 and from study participants to assess how the intervention was experienced and internalized.

Stepped Wedge Trials*

(d) Stepped wedge study including transition period



Time

* Hemming et al., The stepped wedge cluster randomised trial: rationale, design, analysis, and reporting, BMJ, 2015.

Other Examples?



Questions??

